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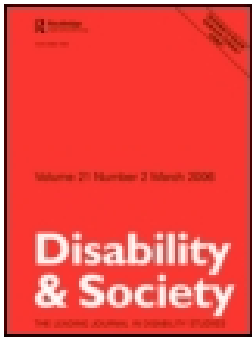
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What is good personal assistance made of? Results of a European survey

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ABSTRACT

This article presents the results of a survey on personal assistance (PA) for disabled people, conducted among PA users and members of the independent living movement in Europe. The survey was developed and implemented in the spirit of emancipatory disability research, and was informed by the social model of disability and the independent living philosophy. Participants were asked to assess a series of characteristics of PA in terms of their impact on users' choice and control. Their responses help identify which characteristics of PA are considered to be enablers of choice and control, which characteristics are perceived as barriers and which characteristics elicit disagreement or lack of consensus among PA users and members of the independent living movement in Europe. Plans for using the results of the survey to develop a tool for evaluating PA schemes are also discussed.

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Disability policy; emancipatory disability research; independent living; personal assistance; social model of disability

Points of interest

- This article looks at the results of a survey on personal assistance for disabled people in Europe.
- The survey was completed by disabled people who use personal assistance and by people who support the ideas of independent living.
- Participants were asked which characteristics of personal assistance help people to have choice and control in their lives, and which characteristics make choice and control difficult.
- The results from the survey are useful because they can help to make personal assistance better.

Introduction

This article presents the initial results of a two-year research project on personal assistance (PA) in Europe, titled 'User-Led Personal Assistance in the

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European Union: A Critical Comparative Analysis'. The research is funded through the European Union's Horizon 2020 research and innovation programme and hosted by the European Network on Independent Living (ENIL).¹ It seeks to involve PA users and members of the independent living movement in co-producing a tool for evaluating PA schemes in terms of their impact on users' choice and control. The work is informed by the social model of disability and the independent living philosophy – the two most prominent twentieth-century expressions of disabled people's struggles for emancipation from institutional confinement, medicalisation and top-down, paternalist control (Oliver 1996; DeJong 1979). The social model conceptualises disability as restrictions of activity imposed by society upon people with impairments (Oliver 1996; UPIAS 1976), while the independent living philosophy asserts that disabled people should have the same opportunities for choice and control in their lives as their non-disabled counterparts (Morris 2004).

PA has been defined by members of the independent living movement as 'a tool which allows for independent living. PA is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed' (European Network on Independent Living, n.d.). The introduction of PA brought about a social policy innovation that promised to transform radically the provision of social support for disabled people. Since the 1980s, user-led PA schemes have enabled many disabled people from the Global North to have control over their support (Evans 2002; Ratzka 1993; Stainton and Boyce 2004), in contrast to provider-led mechanisms such as residential care that have empowered professionals. Consequently, PA has become a major prerequisite for achieving the vision of 'choice and control', embraced by the independent living movement (European Network on Independent Living 2015; Morris 2004). The development of PA schemes has also contributed to the process of deinstitutionalisation that has been actively promoted on national and international levels over the past several decades (Mansell et al. 2007) – consider, for example, the European Disability Strategy 2010–2020 that has committed the agencies of the European Union to:

achieve the transition from institutional to community-based care, including use of Structural Funds and the Rural Development Fund for training human resources and adapting social infrastructure, *developing personal assistance funding schemes*, promoting sound working conditions for professional carers and support for families and informal carers. (European Commission 2010; emphasis added)

The disabled people's movement has been at the forefront of development of PA. The pioneering work of disability activists in Sweden (Ratzka 1993) and the United Kingdom (Evans 2002) led to the adoption of groundbreaking legislation codifying PA in these countries – the Swedish Assistance

Allowance Act (*Lag om Assistansersättning*) of 1994 (Ratzka 2004b; Westberg 2010) and the British Community Care (Direct Payments) Act of 1996 (Evans 2002). More recently, PA has also been introduced in the newer, post-socialist members of the European Union as well – examples include the Czech Republic (Šiška and Beadle-Brown 2011) and Bulgaria (Mladenov 2017a).

The development of PA has been slowed down and, in some cases, reversed by austerity measures that followed the financial crisis of 2007–2008 (Brennan et al. 2016; European Foundation Centre 2012). PA schemes have been subjected to direct and indirect cuts, with some being closed down – such as the Independent Living Fund in the United Kingdom (Disabled People Against Cuts 2015) – while others being made more restrictive, for example, by tightening eligibility criteria, changing the definition of ‘needs’ covered by the scheme (Bolling and Westberg 2017), or introducing workfare conditionality (Mladenov 2017a). Nevertheless, PA has remained one of the most significant innovations in disability policy in the Global North over the last several decades and as such calls for a comprehensive and practically oriented analysis.

In its most empowering form, PA gets organised on the basis of ‘direct payments’, a mechanism for transferring of funds directly to the assistance users that enables them to have full control over the purchasing of their assistance (Ratzka 2004a). Direct payment schemes have been regarded as bringing about empowerment and emancipation to their recipients because through them disabled people become ‘employers’ or ‘contractors’ who either directly recruit, hire and manage their personal assistants or do so through the mediation of independent service providers (Stainton and Boyce 2004). However, there are PA schemes which do not involve direct payments (European Network on Independent Living 2015, 9; for a national example, see Mladenov 2017a). More generally, the characteristics of PA schemes vary widely. Such variety includes different funding arrangements, needs assessment procedures, principles of provision, accountability requirements and working conditions of the assistants. This observation informs the question addressed in the present article: what is good PA made of? More precisely, which characteristics of PA enable choice and control, and which are barriers to disabled people’s independent living?

Over the years, some of the features of PA have been subjected to intense scrutiny and debate. For example, commentators have criticised those PA schemes in which the provision of assistance has been made conditional on participation of users in education and/or employment (Mladenov 2017a; Bonfils and Askheim 2014). In addition, concerted attempts have been made to explain and overcome the poor take-up of direct payments for PA in countries where direct payments have been available (Slasberg and Beresford 2015). Another focal point of heated debate has been the neglect

of the emotional aspect of the relationships between PA users and their assistants in purely instrumental understandings of the role of personal assistants (Shakespeare, Porter, and Stöckl 2017). Related to this, feminist advocates of the 'ethics of care' have voiced concerns about the working conditions of the assistants, many of whom are women from disadvantaged backgrounds (Christensen 2009; Kittay 2018). Others have explored and criticised the marketisation of PA for undermining the welfare state, eroding the collective and grassroots aspects of PA provision, privatising risk and responsibilising service users (Mladenov 2015; Ferguson 2007). This article revisits some of these issues.

The following present the results of a survey that asked PA users and members of the independent living movement in Europe to evaluate a number of characteristics of PA in terms of their impact on users' choice and control. The survey was completed by people residing in 21 European countries (the full list is given in the 'Results' section). Importantly, the characteristics of PA included in the survey did not refer to any actually existing PA scheme but described typical features of PA that are likely to be found in actual schemes. In the following, the methodology of the survey is presented first, and then the results obtained. The main part of the article analyses the results, followed by a discussion of limitations. The development and implementation of the survey has been part of a process of co-producing a tool for evaluating PA schemes. The conclusion of the article outlines plans for the elaboration of such a tool and for its application to actually existing PA schemes. This task is still outstanding and its proper implementation could deliver cross-national evaluations and comparisons of PA schemes from the perspective of PA users and members of the independent living movement.

Methodology

The survey presented in this article was constructed by elaborating a series of statements describing various typical characteristics of PA on the basis of a literature review that included academic papers and civil society reports. The sampling of the papers and reports was purposive (Berg 2001, 32), informed by the aim and approach of the survey as well as by the researcher's previous investigations of PA (Mladenov 2012, 2015, 2017a). Key themes and patterns were identified through content analysis (Berg 2001, 239–267; Weber 1990), which enabled the formulation of 138 statements arranged into five emergent categories: 'context', 'funding', 'needs assessment', 'provision' and 'working conditions'. These categories were not formulated in advance but resulted from thematic clustering of the 138 statements, and it was assumed that the five emergent categories denoted the major dimensions of a typical PA scheme. Thus, 'context' refers to origins, principles,

legislative framings, evolution and impact of PA on users, their families and wider society; ‘funding’ includes details about sources, coverage, form and adequacy of different funding arrangement; ‘needs assessment’ considers assessors’ identities, their training, eligibility criteria for accessing PA, the assessment procedure and its outcome; ‘provision’ subsumes identity of providers, portability of assistance, procedures for recruitment of assistants, limitations on timing and the range of tasks assigned to assistants, and provision of support to users; and ‘working conditions’ covers assistants’ remuneration, employment protection, profile, status in the wider society and access to additional support.

The survey was piloted by asking two members of staff at ENIL to complete it and provide feedback on the comprehensibility of its guidelines and the validity of its statements. Following a subsequent revision, the researcher used the membership network of ENIL to invite assistance users, their organisations and allies to complete the survey. The invitation was open, with no inclusion or exclusion requirements, although the participation of PA users was explicitly encouraged. The instruction was to assess the characteristics of PA described by the 138 statements on a scale from +3 to −3, where +3 meant that the characteristic enabled choice and control to the maximum extent, whereas −3 meant maximum hindrance of choice and control. At the end of the list of characteristics in each category, respondents were given the opportunity to add comments in an open-ended way. The provision of personal information – name, country of residence, use of PA, organisational affiliation and email address – was optional. No information was collected about the living arrangements of the respondents (e.g. living at home or in a residential institutions), and neither were respondents asked to provide information about the kind or degree of their impairments. The full inventory, including the guidelines for its completion and the consent form, is available online (https://enil.eu/wp-content/uploads/2019/04/PA_Inventory.pdf).

The survey was administered online in the period 19 January–4 March 2018, using Google Forms as its platform. Online administration ensured efficiency in collection and processing of data, while a paper version of the survey was available upon request. Information about the survey was distributed via email and ENIL’s newsletter, reaching 1978 addressees in total. This group consisted of ENIL’s 683 individual and organisational members plus 1295 subscribers of ENIL’s newsletter at the time. Since many independent living advocates in Europe are affiliated with ENIL as either members or subscribers of its newsletter, it is assumed that the population targeted by the survey overlaps to a significant degree with what has been regarded as the European independent living movement (Evans 2002). However, considering that the invitation to take part in the survey was open, with no inclusion or exclusion requirements formulated, it is possible (but

unlikely) that some of the people who completed the survey are not (directly) related to the movement.

Formal ethics approval was obtained following the ethics review procedure of the Research Executive Agency of the European Commission. Research ethics was addressed by providing all potential participants with comprehensive information about the project. Any perceived pressure to complete the survey was avoided by clearly stating in the information sheet (attached, as introduction, to the inventory) that the participation in the research was voluntary and that no disadvantage would be incurred by a decision not to participate. Participants were also informed that they could opt out of participation in the research at any point without giving a reason. Anonymity was guaranteed, incentives were not offered and deception was not used in any part of the survey. Subsequent to reading the information sheet, participants were asked to read and sign a consent form, provided that they were interested in and willing to complete the survey.

In terms of its approach, the survey was developed and implemented in the spirit of 'emancipatory disability research' (Barnes 2001; Oliver 1992). This approach stems from the disabled people's movement and its core tenet is that the research process should be controlled by disabled people and their organisations, which translates into several principles including accountability to the community of disabled people, adherence to the social model of disability, making explicit the positionality of the researcher and generating practical outcomes which are useful for disabled people (see Barnes 2001, 7–16). The survey complied with these principles in several respects. First, the survey could be regarded as accountable to the community of disabled people on the grounds that it was hosted by a disabled people's organisation which has been a leading advocate for independent living in Europe. Both the planning and the execution of the survey were realised in consultation with the management and staff of ENIL.

Second, the survey followed the social model of disability by focusing on the barriers and enablers of disabled people's choice and control. As will be explained more fully in the next section, the aggregation of scores assigned by respondents to each of the 138 characteristics of PA included in the survey makes it possible to identify barriers and enablers, while the distribution of these scores (calculated using the statistical measure of 'interquartile range' [IQR]) shows degrees of consensus. The survey was also informed by the independent living philosophy in its use of the concept of 'choice and control' as a normative point of reference – that is, as a measure against which different elements of PA were assessed. Of note here is that the social model and the independent living philosophy are widely (although not universally) regarded as complementary – consider, for example, Barnes' (2007, 349; original emphasis) point that '[d]isabled people's self-organization and

the thinking behind the concept of independent living provided Oliver (1981) with the inspiration for the development of the *social model of disability*, or Jolly's (2009, 3) assertion that '[t]he philosophy of the social model of disability underpins the aims of the independent living movement'.

Third, the positionality of the researcher concerns the methodological and value commitments outlined so far in this article. These commitments were explicitly laid out in the rationale for the survey, as formulated in the research bid which secured its funding. They included the social model of disability, the independent living philosophy and emancipation of disabled people more generally: 'The research will ... be distinctive in its normatively informed approach rooted in the concerns and reflecting the priorities of the European disabled people's movement' (Mladenov 2017c, 6). The researcher himself does not have an (recognised) impairment, and neither is a PA user. However, he has been involved for many years in disability advocacy and shares its emancipatory aims and aspirations.² Moreover, as noted by Barnes (1992, 122):

Emancipatory research is about the demystification of the structures and processes which create disability, and the establishment of a workable dialogue between the research community and disabled people. To do this researchers must put their knowledge and skills at the disposal of disabled people. They do not have to have impairments themselves to do this.

Fourth, from its very inception, the survey was oriented towards generating practical outcomes that would be useful for disability advocates. As will be explained in more detail in the conclusion of this article, the results of the survey will be used to enable evaluation and comparison of PA schemes intended to support advocacy for policy changes. In addition, the results were widely disseminated among disability advocates by publishing regular summary reports of the research process and its findings in ENIL's newsletter (Mladenov 2017b, 2018a, 2018b).

Results

During the six weeks of the survey's implementation between 19 January and 4 March 2018, 54 completed questionnaires were returned. The reasons for this low response rate, which corresponds to less than 10% of ENIL's membership base, are discussed in the later section on 'Limitations'. Assistance users constituted the majority among the respondents, with 35 people (65%) identifying themselves as 'personal assistance users' and 15 (28%) self-identifying as 'non-users'. Fifty-two respondents (96%) stated that they were 'affiliated with an organisation active in the disability field' and 34 (63%) defined their organisation as 'led and controlled by personal assistance users'. These figures suggest that the perspective of PA users and members

of the independent living movement clearly dominated the responses to the survey, in concert with the survey's aim and approach. That said, no statistically significant difference between the answers of users and non-users can be established. More precisely, the difference between the scores assigned by users and those assigned by non-users has statistical significance $p < 0.05$ for only 6 of the 138 statements, but none of these differences retains its statistical significance when the significance level is corrected for multiple testing using the Bonferroni correction.

Of the 48 respondents who revealed their countries of residence, one person reported Indonesia and 47 people reported 21 European countries: Armenia, Austria, Belgium (three respondents), Bulgaria (four respondents), Estonia, France (two respondents), Greece (four respondents), Hungary (four respondents), Ireland, Italy, Luxembourg, Malta, Montenegro (two respondents), Norway (three respondents), Netherlands (two respondents), Romania (two respondents), Serbia (three respondents), Spain, Sweden, Switzerland and the United Kingdom (eight respondents). These results show a slight bias in the sample towards respondents from the United Kingdom (which, however, is itself comprised of four countries) and Southeastern Europe, and some gaps in Central Europe. The prominence of the United Kingdom is unsurprising, considering its rich traditions in disability advocacy and disability studies; the gaps in Central Europe could be attributed to gaps in ENIL's membership in this region.

Of the 138 items or characteristics of PA included in the survey, 100 received a positive aggregate score (AS) and 38 received negative ones, with the maximum/minimum AS being $(54 \times +/ - 3 =) +/ - 162$. Calculating the AS for each item makes it possible to identify which characteristics of PA are perceived by the respondents as the greatest enablers and which ones as the greatest barriers to choice and control. However, perceptions could be revealed with greater precision by also identifying the degree to which they are shared. This could be done by taking into account the dispersion of individual scores – the more dispersed the individual scores, the less consensus there is about the impact of the characteristic on choice and control, and vice versa. One way of estimating dispersal and therefore consensus is by using the statistical measure of the IQR – the difference between the third and the first quartiles of a data set, where the third quartile is the middle value between the median and the highest value, whereas the first quartile is the middle value between the smallest value and the median. The lower the IQR, the higher the consensus, and vice versa. Calculating the IQR makes it possible to identify both the most and the least consensual characteristics of PA. A sheet with raw data detailing the scores for each item, as well as their distribution, is available online (https://enil.eu/wp-content/uploads/2019/04/PA_Inventory_raw_data.pdf).

As far as qualitative information is concerned, of the 54 people who responded to the survey, 16 provided open-ended comments including information, recommendations and critique. In the next sections, these qualitative inputs will be discussed in relation to the quantitative results of the survey (for a more comprehensive presentation and analysis of the qualitative inputs, see Mladenov 2018a). All of the comments have been anonymised, with names of participants and countries substituted by placeholders denoting roles and regions.

Analysis

Enablers of choice and control

One hundred characteristics of PA received a positive AS, which means that, overall, they were perceived by the respondents as enablers of choice and control. Of particular interest are the top enablers – therefore, the 10 characteristics with the highest AS are discussed in the following. All of them achieved an IQR of one or less than one, which suggests that their assessment as top enablers was strongly consensual:

1. The users can choose their personal assistants. (AS: +130; IQR: 0)
2. The assistants are protected by health and safety provisions. (AS: +124; IQR: 1)
3. The appeal procedure (that enables the users to contest the outcome of the needs assessment) is straightforward, transparent and does not entail additional expenses for the user. (AS: +123; IQR: 0.75)
4. The scheme is provided irrespective of family (including marital) situation. (AS: +120; IQR: 1)
5. The users can keep their assistance when moving to another region or local authority within the country. (AS: +120; IQR: 1)
6. The users of the scheme have the opportunity to appeal the outcome of their assessments. (AS: +119; IQR: 0.75)
7. Under the scheme, the user determines the times when assistance will be provided, including during nights, weekends, holidays, etc. (AS: +119; IQR: 0.75)
8. The scheme is underpinned by the independent living philosophy and/or the social model of disability. (AS: +118; IQR: 1)
9. The users can dismiss their personal assistants. (AS: +118; IQR: 1)
10. The provision of PA under the scheme is recognised as a (human, civil, social) right. (AS: +117; IQR: 1)

These 10 characteristics are drawn from four dimensions of PA, as defined by the survey: provision (statements 1, 5, 7 and 9), needs assessment

(statements 3, 4 and 6), context (statements 8 and 10) and working conditions (statement 2). Let us briefly consider the enablers in each of these four dimensions in turn. The greatest enablers in provision are identified as having choice and control over the 'who' (statements 1 and 9), the 'where' (statement 5) and the 'when' (statement 7) of PA. This outcome is in line with the definition of PA promoted by European independent living advocates, as summarised by Ratzka (2004a, 3): 'the user decides who is to work, with which tasks, at which times, where and how'.

The most enabling characteristics of PA in the domain of needs assessment emerge as the possibility to appeal the outcome of the assessment (statements 3 and 6) and the decoupling of eligibility from the family situation (statement 4). The possibility to appeal increases the control of the user over the 'gatekeeping' of social support and frames PA as right rather than privilege (see Westberg 2010, 22). The decoupling of eligibility from the family situation means that having access to informal care (by, for example, living with one's parents or spouse) should not be used as a basis for denying PA – otherwise, 'a serious barrier to independent living and self-determination of disabled people and their family members [emerges]' (Angelova-Mladenova 2017, 35).

Among the greatest enablers of PA identified by the respondents are also two contextual characteristics that concern the grounding of PA in the independent living philosophy and/or the social model of disability (statement 8), as well as recognising PA as a right (statement 10). Here, the responses to the survey suggest that clarity about the guiding principles of the disabled people's movement is a precondition for promoting policies and practices that empower and emancipate (notwithstanding that these principles have been subjected to internal debate and critique over the years; see, for example, Shakespeare 2006; Shakespeare, Porter, and Stöckl 2017). Historically, user-led PA has been developed within the independent living movement (DeJong 1979; Evans 2002; Ratzka 1993), whose close links with the social model of disability have been repeatedly emphasised by scholars and activists (Barnes 2007; Jolly 2009). In a recent report on PA, Shakespeare, Porter, and Stöckl have argued that:

Training in the social model of disability would be a useful foundation for good personal assistance, for example, the role of personal assistants as helping to overcome disabling barriers. Disabled people's organisations are in a good place to provide this training. (2017, 35)

As far as recognition of PA as a right is concerned (statement 10), the significance of this characteristic could be understood with reference to Oliver's (1996, 63–77) point that, in disability policy, the rights-based approach should be prioritised over the needs-based one because the shift from 'needs' to 'rights' means transition from charity to entitlement, from passivity

to activity and from professional domination to self-determination of disabled people (Mladenov 2017b).

Finally, the top enabler in the domain of working conditions concerns assistants' health and safety (statement 2). It should be noted here that independent living advocates have been criticised for disregarding the working conditions of personal assistants – for example:

the empowerment of the disabled person does not offer protection from exploitation to the assistant. The discourse of direct payments and PAs, which has evolved from the social model, has, to date, been managerial (Vasey 2001) and devoid of a language of mutuality, partnership and interdependence. (Watson et al. 2004, 338)

Since assistance work has been overwhelmingly feminised and transnationalised (Shakespeare, Porter, and Stöckl 2017, 11), this has opened up possibilities for exploitation of (migrant) women by disabled people (Watson et al. 2004, 339). Along this line, a tension has emerged between the disabled people's movement and feminist activists and thinkers, particularly the advocates of the 'ethics of care' who have highlighted the supposedly neglected plight of 'carers' within contemporary PA schemes (Christensen 2009; Kittay 2018).

However, the results of this survey suggest that many PA users and members of the independent living movement are genuinely concerned about the assistants – the responses clearly put the good working conditions of the assistants among the greatest enablers of choice and control. Beside statement 2 above, there are two other closely related characteristics of PA that received comparably high AS and low IQR: 'The wages of the assistants are protected by minimum wage regulations' (AS: +114; IQR: 1.75) and 'The assistants are entitled to benefits such as social security and paid leave (annual, sick and parental)' (AS: +114; IQR: 1). Moreover, in their qualitative answers, the respondents similarly emphasised the importance of working conditions, for example, by criticising the low wages or job precarity of the assistants in their countries: 'There is no[t] enough assistants as the extreme[ly] low wages' (PA user, Eastern Europe); 'The service providers are being persuaded to engage assistants by service not by the work contract because it's less obligatory in relation to paid absence, replacement or deadline for payment' (PA user, Eastern Europe). Such highlights support the more general point that the interests of 'care-givers' are commensurate with the interests of 'care-receivers' because '[b]oth advance decommodification of labour and both presuppose deconstruction of self-sufficiency' (Mladenov 2016, 1238).

Barriers to choice and control

As far as the barriers to choice and control are concerned, 38 characteristics of PA received a negative AS. The 10 items with the lowest AS are discussed

in the following. Of these, six characteristics achieved an IQR of one or less than one (given in the list in *italic*):

1. *The assistants are appointed by the provider, without the involvement of the user.* (AS: −125; IQR: 0)
2. *Under the scheme, assistance is bound to a location (e.g. it is provided only at the user's home).* (AS: −124; IQR: 0.75)
3. *The scheme deteriorates by incorporating measures that restrict the choice and control of the users.* (AS: −116; IQR: 1)
4. *The scheme is limited by a 'cost ceiling' and users whose support costs more are directed towards traditional services (e.g. residential institutions).* (AS: −115; IQR: 1)
5. The scheme is used as an excuse for cutting expenses for 'social care'. (aC: −108; IQR: 1.75)
6. *Policy-makers and other stakeholders (e.g. the media) misunderstand, misuse or misrepresent the scheme.* (AS: −107; IQR: 1)
7. Assistants are not allowed to perform tasks related to health care (even after delegation or approval by medical professionals). (AS: −103; IQR: 2)
8. Under the scheme, assistants work fixed hours (e.g. from 9:00 am till 5:00 pm). (AS: −99; IQR: 2)
9. *The scheme is subjected to cuts (e.g. eligibility is tightened, 'assistance hours' are reduced, conditionality is introduced, etc.).* (AS: −97; IQR: 1)
10. There is a pre-defined list of tasks that the assistants can do. (AS: −86; IQR: 3)

In the survey, these top 10 barriers are included in three different dimensions of PA: provision (statements 1, 2, 7, 8 and 10), context (statements 3, 5, 6 and 9) and funding (statement 4). According to the respondents, the greatest barriers in provision emerge when the scheme restricts the users' choice and control over the 'who' (statement 1), the 'where' (statement 2), the 'what' (statements 7 and 10) and the 'when' (statement 8) of PA. These barriers complement, as their negative counterparts, the top enablers in provision discussed in the previous section and confirm that the essence of user-led PA is that 'the user decides who is to work, with which tasks, at which times, where and how' (Ratzka 2004a, 2004b, 3). At the very heart of the mechanism is the opportunity to choose one's personal assistant – the statement 'The assistants are appointed by the provider, without the involvement of the user' achieved the lowest AS of all items (−125), while its opposite ('The users can choose their personal assistants', discussed in the preceding section) achieved the highest AS (+130); moreover, these two characteristics of PA achieved the highest

possible degree of consensus (IQR: 0) that no other characteristic included in the survey achieved.

The top barriers in the dimension of context concern the introduction of restrictions and/or cuts to PA (statements 3, 5 and 9), as well as ideological distortions (statement 6). The focus on cuts reflects the widely shared concern of PA users and members of the independent living movement about austerity and its negative impact on PA in the aftermath of the financial crisis of 2007–2008 (Brennan et al. 2016; European Foundation Centre 2012). Disquiet about insufficient funding finds expression in the open-ended comments to the survey as well; for example, 'Unfortunately in all schemes [provided in the country] there[']s a lack of funding, which makes buying [ade]quate care with a personal budget really hard' (PA user, Western Europe). In their comments, respondents highlight a number of related problems – that the amounts of personal budgets are inadequate, that funding per assistance hour or the number of assistance hours allocated to users is too low, that cuts have eroded PA provision and that funding does not cover all of the expenses associated with PA, including overhead expenses, users' training and peer support.

As far as ideological distortions (statement 6) are concerned, the disabled people's movement has been engaged in fierce interpretive struggles from its very inception (UPIAS 1976). Meaning is political – '[d]efinitions guide actions, shape identities, underpin policies and justify public spending. Moreover, definitions maintain or undermine hierarchies, they are means of social control or liberation' (Mladenov 2017b). The disabled people's movement has fought to substitute definitions imposed by dominant others such as medical professionals and public administrators with definitions of its own (European Network on Independent Living, n.d.). However, together with their inclusion in the mainstream, terms such as 'independent living' and 'personal assistance' have 'often been exploited and misused to profit organisations, charities and disability business which are not run and controlled by disabled people' (Jolly 2009, 2). Moreover, ideological distortions of the meaning of 'independence' have been used to justify cuts – in effect, 'terms coined by the disabled people's movement [have been borrowed] to underpin major withdrawal of welfare support' (Roulstone 2015, 678). The concern that key stakeholders 'misunderstand, misuse or misrepresent' PA, reflected in assessing nearly unanimously (IQR: 1) statement 6 as a top barrier to choice and control (AS: –107), finds expression in the qualitative responses to the survey as well:

In [the country] there is no political or social awareness of independent life. Personal assistance is seen as a substitute for caregivers (especially [for] elderly people). We need a greater social awareness. (Non-user, Southern Europe)

Finally, the top barrier in the domain of funding (statement 4) refers to limitations imposed on the costs of PA for individual users. This characteristic

of PA is associated with the theme of cuts discussed earlier, but it also relates to the interface between PA and traditional services such as residential institutions. Historically, user-led PA has been an important facilitator of deinstitutionalisation (Evans 2002) – therefore, restrictions imposed on PA are bound to support or justify institutional care, thereby becoming a major barrier to choice and control.

Non-consensual characteristics of PA

Besides the greatest enablers and the greatest barriers, the third group of items which are of particular interest are the least consensual characteristics of PA, approximated statistically by identifying the items in the survey that received the highest values of IQR. These are the statements which attracted the most diverse scores and can therefore be regarded as having the potential to elicit most disagreement among PA users and independent living advocates. Nine characteristics of PA received an IQR value of more than three:

1. The scheme requires medical certification of the applicant as a prerequisite for applying. (AS: –26; IQR: 4.75)
2. The scheme is provided irrespective of the degree of impairment. (AS: +46; IQR: 4)
3. The scheme does not allow for family members to be recruited as personal assistants. (AS: –23; IQR: 4)
4. PA under the scheme is provided in kind. (AS: –34; IQR: 4)
5. The assessors are trained by professionals (e.g. medical professionals, social workers, psychologists, etc.). (AS: –48; IQR: 4)
6. The providers are subjected to licencing/accreditation/certification by an independent body. (AS: +42; IQR: 3.75)
7. The scheme promotes the creation of markets of assistance services where service providers compete to attract customers. (AS: +11; IQR: 3.75)
8. Assistants are regarded by the users in instrumental terms, for example as ‘arms and legs’ or ‘staff’. (AS: +8; IQR: 3.75)
9. The training of the assistants is provided by professionals (e.g. medical professionals, social workers, psychologists, etc.). (AS: –46; IQR: 3.75)

These nine items achieved an AS of between –48 and +46, which positions them around the middle of the –3 to +3 scale or around zero, defined in the survey as meaning ‘that what is described neither hinders nor enables user’s choice and control, or that it is irrelevant’. However, the dispersion of individual scores, as reflected in high IQR values, suggests that these

characteristics of PA are far from neutral or irrelevant. The dimensions of needs assessment (statements 1, 2 and 5) and working conditions (3, 8 and 9) are most prominently represented, together with funding (statement 4), provision (statement 6) and context (statement 7).

The comprehensive analysis of these non-consensual items is beyond the scope of this article. They include issues that have traditionally been divisive within the disabled people's movement such as the setting up of impairment-based criteria for access (statement 2), the role of family members as assistance workers (statement 3) and the preference for in-kind as opposed to cash-based arrangement of support (statement 4); as well as meta-issues such as the role of professionals in training activities (statements 5 and 9) and the oversight of provision (statement 6). That said, there are three non-consensual characteristics that merit special attention. They pertain to three different dimensions of PA – needs assessment (statement 1), context (statement 7) and working conditions (statement 8) – and are singled out for analysis here because of their traction within current disability scholarship. In the following, some tentative proposals for their non-consensual standing are formulated, drawing on recent disability studies literature.

The statement 'The scheme requires medical certification of the applicant as a prerequisite for applying' was assessed by 28 respondents as a barrier to choice and control, by 18 respondents as an enabler and by eight respondents as neither. The statement's AS is negative (−26), although not as strongly negative as the AS of most of the other barriers (of the 38 barriers, this item ranks 31). Medical assessment of disability has been criticised by disability scholars (Admon-Rick 2014; Mladenov 2011) because it individualises disability, institutionalises ableist misrecognition and is often experienced by the people subjected to it as alienating, objectifying and demeaning (Broyer 2011). However, in the present survey 18 respondents assessed medical certification as an enabler of choice and control by assigning positive scores to the respective statement. How to explain this dissenting perspective that arguably supports the medical model of disability?

By claiming direct access to the applicant's objective 'condition', medical assessment promises to circumvent the subjective intentions, interests and motivations not only of the persons being assessed but also of the assessors. This may be a false promise,³ but it cannot be easily dismissed (Stone 1984, 127–139). Accordingly, medical certification seems to guarantee not only just distribution of limited resources by ensuring that only those 'objectively' in need get support, but may also be regarded as a defence against attempts to cut benefits and support by making disability less negotiable or by limiting the administrators' attempts to efface disability, especially in times of austerity and anti-disability rhetoric. As pointed out by Vehmas and Watson:

Recognizing impairment effects [i.e. the restrictions to functioning which arise from impairments rather than from disability or societal oppression – the term is coined by Carol Thomas] is necessary in order to secure proper treatment and social arrangements that enhance disabled people's well-being and social participation. (2014, 646)

The second non-consensual characteristic of interest concerns marketisation of disability support: 'The scheme promotes the creation of markets of assistance services where service providers compete to attract customers'. In contrast to the statement on medical certification, this one achieved a marginally positive AS of +11, with 27 respondents assigning positive scores, 17 assigning negative ones and 10 choosing zero. Here, the lack of consensus among the participants in the survey seems to reflect tensions between liberal and social-democratic visions of disability justice. The arguments for the creation of markets of assistance services and for stimulating competition between service providers has been voiced by some liberal independent living advocates, and most prominently by Adolf Ratzka, one of the pioneers of independent living and PA in Europe:

How can freedom of choice and quality through competition be best promoted? Is it by having state monopolies provide goods and services as in the days of the poor houses before the welfare state instituted the pension system? ... Cash benefits open the way to demand-driven markets where suppliers listen to what consumers want. Services in kind are characteristic for supply-driven markets where you get what's on the shelf, where one size has to fit all, where your individual combination of resources, needs and preferences is not acknowledged, where you are denied your identity as a unique person. (Ratzka 2012, 3)

However, other sections of the disabled people's movement have distanced themselves from this strongly consumerist and market-friendly version of the independent living philosophy. For example, Beresford (2009, 4) has argued that the model of direct payments 'was [originally] far from being a consumerist model. On the contrary, direct payments were a collectively inspired means of supporting the rights and liberation of service users'. Reactions against marketisation of 'independence' have intensified in the era of post-2008 austerity (Roulstone 2015). Moreover, historical analysis has suggested that:

over the last three decades the demands of the DPM [disabled people's movement] ... have been 'resignified' and, similarly to the demands of second-wave feminism, have been appropriated to serve the interests of capital in its historically renewed, neoliberal form. (Mladenov 2015, 455)

The third non-consensual characteristic to be highlighted here refers to the relational aspects of PA: 'Assistants are regarded by the users in instrumental terms, for example, as "arms and legs" or "staff"'. This item's AS is marginally positive (+8), with 22 respondents assigning positive scores, 16

assigning negative ones and 16 remaining neutral by assigning zero. In a research report published in 2017, Tom Shakespeare and colleagues have associated the instrumental conception of the PA relationship with the original tenets of the independent living movement, while pointing out that 'recent literature has begun to question whether the assistive relationships can ever be as pragmatic or professional as Independent Living philosophy would proclaim' (Shakespeare, Porter, and Stöckl 2017, 4). However, the authors have also emphasised that even though 'PA relationships involve characteristics features of friendship (such as emotional attachment and shared interests) they also retain fundamental qualities of the employer-employee relationship' (2017, 5).

The results of this survey reflect the tension discussed by Shakespeare and his colleagues. Complementing the statement about regarding assistants 'in instrumental terms', the survey included two other statements describing alternative models of relationships: 'Assistants are regarded by the users in dialogical terms, for example, as "colleagues"' (AS: +39; IQR: 2) and 'Assistants are regarded by the users in emotive terms, for example, as "friends" or "part of the family"' (AS: -29; IQR: 2). The relatively lower IQR of these two items indicates a greater degree of consensus. Nevertheless, both statements similarly divide respondents into three groups – the first attracted 30 positive, 12 negative and 12 neutral scores, while the second attracted 13 positive, 25 negative and 16 neutral scores. In the final analysis, the 'dialogical' model of the PA relationship emerges as the preferred one, although the choice of the relationship model may also be a matter of individual preference or style – as one participant pointed out in an open-ended comment:

Some [disabled people] will require a PA to fade into the background until needed for a specific task and undertake it almost robotically so as not to dominate or take focus from the disabled person, while others will choose a 'friends and family' type relationship where they derive encouragement and affection from staff. (Non-user, Western Europe)

Limitations

The critical review of the design and implementation of the survey reveals several limitations that need to be taken into account when interpreting its results. To begin with, the survey's impersonal, online mode of implementation, coupled with its sheer length, conditioned a low response rate which limits the representativeness of its results. Face-to-face surveys yield higher response rates but are much costlier, which puts them beyond the reach of small-scale research projects hosted by grassroots advocacy organisations like the present one. It should also be noted that the intention of this survey

was primarily consultative rather than explorative – to hear from assistance users and members of the independent living movement in Europe, rather than to identify with statistical precision the perceptions of this group.

As far as the length of the survey is concerned, the issue was flagged up in the open-ended comments by one of the respondents thus: 'it's a long enough survey, and people reading it might have a disability (I do). Did you really need to make the survey so long?' (non-user, Western Europe). This comment suggests that the length of the survey makes it inaccessible for people with certain types of impairments who tend to get tired more quickly. PA is a complex arrangement that includes many elements. As an example, in the model described by Ratzka (2004a), PA is constituted by a number of interrelated features, including needs assessment procedures, funding and accountability arrangements, appeal options, training activities, peer support and so forth. Taking this complexity on board calls for a long description (Mladenov 2012). But although it was dictated by the subject matter, the length of the survey most certainly had an impact on its response rate (and thereby on the representativeness of its results) by way of being a deterrent and/or a barrier to participation.

Another limitation of the survey is that its sample was not perfectly random. To increase the response rate, personalised emails with invitations to complete the survey were sent to the members of ENIL's Board of Directors and its Youth Network Board. However, this method of dissemination also increased the likelihood that the addressees' opinions would be over-represented in the results. That said, most of the members of the two boards of ENIL are PA users themselves and many of them are also leaders of independent living organisations of disabled people from different European countries. Consequently, the over-representation of their views, rather than distorting the results, could be regarded as strengthening their focus in line with the survey's intentional bias towards the views of PA users and members of the independent living movement in Europe.

The feedback provided by the respondents in the open-ended sections of the survey suggests that the survey's formulations were themselves sometimes perceived as limitations. One complaint voiced in several comments concerned a lack of clarity, for example: 'The question about rurality is not clear – does it ask if ONLY disabled people in rural areas should access the scheme?' (non-user, Western Europe). Related to this, there were several suggestions for (minor) revisions of some of the statements or inclusion of new ones: 'The Agency section could have one more option: "Combination of the above"' (non-user, Southern Europe). For some, English language was an issue: 'A bit complicated [E]nglish and how to answer can be wrong[l]y underst[ood]' (PA user, Northern Europe). Terminological preferences were also questioned: 'I and many disabled people find the term "user" pejorative' (non-user, Western Europe).

The survey was constructed following a comprehensive review of existing literature on PA, and the validity of its statements was tested by piloting the survey among colleagues at ENIL. Notwithstanding such precautions, some of the statements obviously remained fuzzy or open to multiple interpretations, while the use of English language in a multi-lingual context created a communicative barrier that made the survey inaccessible for some people. As far as the term ‘user’ is concerned, it was applied in concert with the usual practice at ENIL. Although this term may be disliked or even considered offensive by some disabled people, it is common in research on PA done by both disability advocates and scholars (for example, Ratzka 2004a; Shakespeare, Porter, and Stöckl 2017).

Finally, the very response format of the survey (i.e. the scale from –3 to +3) may be regarded as yet another of its limitations. Some respondents were concerned about fixing a score because they perceived the assessment of some of the statements as dependent on the assessment of others or on individual circumstances, for example:

Some of these questions are very ‘black or white’ ... should assistants have extra payments made for travel? Well, it depends on how well they are paid. Should users of the scheme be required to contribute financially to the service? Yes, if they are very wealthy! (Non-user, Western Europe)

One of the respondents even reformulated the scale to fit their own understanding of the task: ‘I put –3 for absolutely no, 0 for “I don’t know this info” or neither no or yes, 3 for absolutely yes’ (n/a, Eastern Europe). The choice of the response format was dictated by the attempt to quantify responses. Quantification is, by definition, reductive and is usually associated with scientific abstraction, but it has its place in emancipatory disability research (Barnes 2001, 12). Without quantification, cross-country comparisons are more difficult – however, such comparisons provide PA users and their organisations with powerful advocacy arguments.

Conclusion

This article has discussed the results of a survey on PA that asked PA users and members of the independent living movement to identify what enables and what hinders the user’s choice and control among a list of typical PA characteristics. According to participants, the greatest enabler of choice and control in a PA scheme is the opportunity to choose one’s personal assistant. Other important and strongly consensual enablers include opportunities to appeal the outcome of the needs assessment and to have control over the timing of the assistance. The provision of good working conditions for the assistants also features prominently among the top enablers. As far as the greatest barriers are concerned, they include restrictions over the ‘who’, the

‘where’, the ‘what’ and the ‘when’ of PA. Of particular concern are cuts and/or funding restrictions imposed on PA.

These results provide some guidelines for the future developments of disability policy in the European Union. As mentioned in the introduction to this article, the European Disability Strategy 2010–2020 recommends the development of PA funding schemes as a means to achieve the transition from institutional to community-based care (European Commission 2010). It is crucial that such schemes are not provider imposed or provider centred but follow the suggestions of PA users and members of the independent living movement about what good PA is made of. That said, the results of the survey also highlight some characteristics of PA that did not elicit consensus among its respondents – for example, providing access to PA irrespective of the degree of impairment, restricting the recruitment of family members as assistants or organising provision in kind. In the article, three of the least consensual characteristics of PA were discussed more extensively due to their relevance in contemporary debates within disability studies – the requirement of medical certification in applying for PA, the promotion of PA markets and the instrumental treatment of assistants by the users.

During the next stage of the research, the results of the survey will be used to construct and pilot a checklist for evaluation of PA schemes.⁴ Each item in this checklist will be assign a ‘weight’ based on the score it has achieved in the survey. The checklist will then be used to create and compare quantitative profiles of PA schemes from several European countries. Notably, the development and piloting of such a checklist will be informed not only by the results, but also by the limitations of the survey’s design and implementation. As discussed earlier, these limitations include a low response rate, a not perfectly random sample, some occasionally unclear formulations, preference for English as a medium of communication and a relatively rigid response format. Taking these issues on board, the checklist will include an option to flag statements that are unclear or inapplicable to the schemes being assessed; and it could also be translated into the languages of its application, depending on resource availability.

In the longer run and depending on its outcomes, the piloting of the checklist might feed into a revised survey with refined formulations and an improved response rate, which, on its behalf, might inform an ‘upgrading’ of the checklist. Repeated applications of the survey seeking higher response rates would help identify more precisely the validity of the survey items and response format, as well as to determine the survey’s reliability. Last but not least, seeking responses from a wider circle of PA users is compliant with the principles of ‘emancipatory disability research’ (Barnes 2001; Oliver 1992), particularly in view of strengthening the research’s accountability to disabled

people and developing further its practical relevance for independent living and social inclusion.

Notes

1. ENIL is a Europe-wide disability advocacy organisation defending the rights of disabled people to live independently and to be included in society. ENIL has strong historical roots in the independent living movement. The organisation was founded in 1989 by disabled activists including Ratzka (1993) and Evans (2002), who recounts: 'The founding of the European Network on Independent Living, ENIL was one of the most significant events in Europe for the Independent Living Movement. ENIL was founded in 1989. It started when over 80 disabled people, most of whom were personal assistance users, from 14 different European countries, congregated at the European Parliament in Strasbourg to discuss issues of concern on Independent Living. This ended up being an historic event because the main outcome of this meeting of minds was the establishment of ENIL and hence for the first time there was a co-ordinated approach for Independent Living at a European level' (Evans 2002, 13–14). Since then, ENIL has been at the forefront of campaigning and research on user-led PA and many of ENIL's members share this commitment. The organisation's work is based on the principles of solidarity, peer support, self-representation, cross-disability and self-determination.
2. In the period 2000–2009, the researcher worked on a contractual basis for the Centre for Independent Living – Sofia, a disabled people's advocacy organisation that has been campaigning for disability rights in Bulgaria since mid-1990s.
3. The medical-productivist (Mladenov 2011) determination of disability as 'decreased ability to work' on the basis of clinically identifiable impairment(s) is problematic even on its own terms, because 'in an important way it sidesteps the key issue of disability: what is it that prevents people from working? In most instances, the cause is not some identifiable physical phenomenon but a complex set of interacting factors involving individual and family history, the state of the economy, and cultural and psychological as well as biological factors' (Stone 1984, 134).
4. The PA Checklist was piloted while the present article was undergoing review. The report on the pilot application of the checklist is available online (https://enil.eu/wp-content/uploads/2019/02/Mladenov_Pokern_Bulic-PA_Checklist.pdf).

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